

**DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION
Centers for Disease Control and Prevention/
Agency for Toxic Substances and Disease Registry**



**Joint Meeting of the
Ethics Subcommittee of the
Advisory Committee to the Director, CDC
and the
CDC Public Health Ethics Committee
February 25-26, 2009**

Minutes

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Acronyms Used in This Report

ACD	Advisory Committee to the Director
ATS	American Thoracic Society
CDC	Centers for Disease Control and Prevention
DFO	Designated Federal Official
DGMQ	Division of Global Migration and Quarantine
DHS	Department of Homeland Security
DOE	Department of Education
DOT	Department of Transportation
HHS	Health and Human Services (Department of)
MDR-TB	multi-drug resistant tuberculosis
NCHHSTP	National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention
OWCD	Office for Workforce and Career Development
PHEC	Public Health Ethics Committee
SOFA	sequential organ failure assessment
SOP	Standard Operating Procedure
STD	Sexually Transmitted Disease

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ETHICS SUBCOMMITTEE OF THE
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AND THE
CDC PUBLIC HEALTH ETHICS COMMITTEE
February 25 – 26, 2009
Atlanta, Georgia**

Minutes of the Meeting

February 25, 2009

Introductory Remarks and Overview of Meeting Goals

**Bruce Jennings, MA
Chair, Ethics Subcommittee**

At 1:07 PM, Mr. Bruce Jennings called the Joint Meeting of the Ethics Subcommittee of the Advisory Committee to the Director, Centers for Disease Control and Prevention (CDC) and CDC's Public Health Ethics Committee (PHEC) to order. He reviewed the meeting agenda and goals. The meeting goals were as follows:

- Share reflections in memory of Dr. Thomas Hooyman (former Chair of the Ethics Subcommittee who died following a motorcycle injury in November 2008).
- Review progress on development of ethics guidance documents relating to use of travel restrictions and ventilator distribution
- Discuss expectations relating to Ethics Subcommittee members' responsibilities and workload
- Provide Ethics Subcommittee members with background information on social determinants of health research and related CDC activities and develop an implementation plan for addressing the role of social determinants of health in health reform efforts
- Update Ethics Subcommittee members on progress in developing the web-based public health ethics course and on selection of new members for the Ethics Subcommittee

A list of attendees is included as Appendix 1.

Reflections in Memory of Dr. Thomas Hooyman and Plans for Commemoration

Comments and reflections on Dr. Thomas Hooyman were offered by various members of the Ethics Subcommittee and PHEC. In addition, Bruce Jennings read a statement on behalf of Dr. Ruth Macklin, former Chair of Ethics Subcommittee, and Drue Barrett read a statement by Janet Lee, Technical Services Librarian at Regis University, regarding the establishment of a library in memory of Dr. Hooyman in Ethiopia. In addition, two of Dr. Hooyman's colleagues, Dr. Debra Bennett-Woods, and Dr. Thomas Leininger, participated by sharing their remembrances of Dr. Hooyman and expressing Dr. Hooyman's enthusiasm for his work with CDC.

Dr. Barrett informed the group that in honor of Dr. Hooyman, CDC will create an annual Thomas Hooyman Memorial Public Health Ethics Lecture, and Dr. Debra Bennett-Woods will be the first speaker. She also noted that members of PHEC donated funds to Ethiopia Reads in memory of Dr. Hooyman.

Ethical Guidance for Use of Travel Restrictions

Kathy Kinlaw, MDiv, Emory University, Ethics Subcommittee Member
Vanessa Northington Gamble, MD, PhD, George Washington University, Ethics Subcommittee Member
Robert Levine, MD, Yale University, Ethics Subcommittee Consultant
Clive M. Brown, MD, MPH, Division of Global Migration and Quarantine
Martin Cetron, MD, Director, Division of Global Migration and Quarantine

Participating by telephone, Clive Brown, MD, Acting Associate Director for Science, Division of Global Migration and Quarantine (DGMQ), CDC, presented an overview of the need for ethical guidance for use of travel restrictions to control the spread of infectious illnesses. He also provided an overview of the standard operating procedures (SOP) document that CDC is developing regarding use of newly developed travel restriction tools. The primary audience for the SOP document is CDC staff manning quarantine stations. The ethical considerations section developed by the Ethics Subcommittee Travel Restrictions Workgroup is meant to be inserted into this SOP document

Martin Cetron, MD, Director, DGMQ, stressed that CDC has a covenant of trust with the public, but they also have regulatory responsibility. He reported that the protocols and procedures put into place as a result of the May 2007 incident with the traveler with multi-drug resistant tuberculosis (MDR-TB) are working well. Cross-agency collaborations and state and federal relationships have been effective.

Dr. Cetron explained the process that occurs when a person with a highly infectious illness attempts to travel on a commercial airline. This process involves collaboration between the local and state health department, CDC, the Department of Homeland Security (DHS), and local law enforcement. The contagious person is placed on a Public Health Do-Not-Board list. If they attempt to check in at an airport, they are prevented from boarding the plane and can be isolated at the airport and transferred to the county health department's care.

Ms. Kinlaw reviewed the draft of the ethics section for insertion into the travel restrictions SOP document. She noted that the process for creating this document was different from other documents produced by the Ethics Subcommittee. In this case, CDC members of the Travel Restriction Workgroup drafted much of the document and the Ethics Subcommittee members provided feedback. She reminded everyone that this section is part of a larger SOP. The goal is to have this section provide ethical considerations to support the rest of the SOP. A number of brief examples are incorporated into the document in order to make it accessible and useful.

The main ethical concepts in the document are:

- Protecting community interests while respecting individual rights
- Proportionality
- Social and distributive justice
- Beneficence
- Transparency and clear communication
- The responsibility to maximize preparedness and to work collaboratively with other public health agencies to address public health threats
- Global responsibility
- Respecting individuals' privacy while protecting the community

The document recognizes that CDC collaborates with other agencies and entities and that the process of implementing travel restrictions requires the sharing of private information among the agencies. The document also addresses making reasonable accommodations where needed and highlights concepts relating to social and distributive justice and beneficence.

Discussion Points

"Do No Harm"

It was noted that the document focuses on "do no harm" as part of the discussion of beneficence, but the document also supports minimizing possible harms. There is an obligation to maximize benefit while minimizing harm. "Do no harm" is a medical maxim that prohibits doing individual harm as a means of bringing about public good. In the case of quarantine, however, public health officials are limiting individual liberties for the public good. The phrase "do no harm" may not belong in this section of the document, as it applies to clinical ethics. The Subcommittee acknowledged the struggle with the different "languages" of public health ethics versus clinical ethics.

Inclusion of a "Boilerplate" Statement in Ethics Subcommittee Products

It was suggested that it might be useful to develop "boilerplate" language for all of the documents being developed by the Ethics Subcommittee on the ethical foundation justifying public health interventions. Research ethics could provide a useful analogy. Research ethics provide guidance for acceptable conduct of research activities. There is, however, an ethical imperative to conduct research. A "boilerplate" statement could establish the ethical imperative of public health. In the interest of time the Ethics Subcommittee agreed that the travel restriction document work should proceed without this language. Dr. Cetron pointed out that the SOP document is a living document and language can be added at a later time.

Justification of Restriction of Individual Freedoms and Liberties

In general, freedom of movement and other interests are restricted when a person is prevented from traveling or when a person is isolated or quarantined. In order to justify interventions that restrict individual freedoms to protect the public good, the risk to the public has to be serious and likely, and the measure taken should have a high probability of success. Then, the least restrictive of all available measures should be taken. These decisions should not be arbitrary. Putting these ideas into a broad context and then narrowing them to the specific topic of travel restrictions could be helpful.

It was noted that opposition should not be created between community interests and individual rights when the two can complement each other. Because no person has a right to infect others with a serious illness, an individual's liberty is not being infringed upon if his freedom is restricted to prevent him from harming others. In this instance, CDC is not taking away liberties, but rather is exercising the appropriate roles and functions of public safety and public health. What is important is the degree of risk involved and the likelihood that a person will infect others. If others will likely be infected if the person travels, then under the circumstances, the person does not have a legitimate interest or liberty to board an airplane.

The analogy of traveling with an infectious disease and driving while intoxicated was introduced. Most Americans would probably agree that restricting an intoxicated person from driving a car is not restricting his freedom. Americans have the freedom to drive, but not when intoxicated. Americans also have the freedom to travel by air, but they do not have a right to put others in danger, as they would do by traveling with a highly infectious disease. The group debated this point, noting that even though the restriction is justified, it is still a restriction.

Regarding social justice, when justifiable restrictions are placed on people's liberty, there will be concerns regarding disparities and discrimination. It was noted that some infectious diseases, such as TB and MDR-TB, may be more common among persons of lower socioeconomic status and of certain ethnicities. For this reason, the principle of fairness is important when making decisions. There are examples of mandatory public health measures at the state level that were discriminatory and not based on science. That history makes it crucial to be overly careful to implement procedural safeguards. To address this point, the document intentionally refers to community interest while respecting individual rights. It stresses that travel restrictions should be based solely on clinical and public health information and never on the individual's financial status or group membership (e.g., ethnicity, race, religion, gender, or citizenship).

Action and Implementation of the SOP

It was suggested that a table that connects recommended actions with ethical principles would be useful. In addition, the Ethics Subcommittee could potentially assist CDC in implementing the guidance document. Health departments do not see many of these cases, and because of staff turnover, they may not have an opportunity to consider these points "in the field." Separate from this document, the Subcommittee could consider creating a one-page checklist of points to consider for those in the field. It was noted that the larger SOP contains various checklists, and CDC will continue to develop these tools. The Ethics Subcommittee Travel Restrictions Workgroup will assist in reviewing cases and could produce such a checklist from a case review.

Other Points Discussion

It was noted that the last section of the document addresses legal considerations and technical safeguards. While it is important to discuss the legal context of traveler restrictions, some thought that section could be a separate document.

The full SOP document is in the clearance process soon; however, Dr. Cetron agreed to share it with Ethics Subcommittee members in order to assist them in their review of the ethical considerations section.

It was requested that additional comments be e-mailed to Dr. Barrett by March 6.

Next Steps

The Ethics Subcommittee requested that the Travel Restrictions Workgroup consider the suggestions made during the discussion and that they be given an opportunity to review the revised ethical considerations section prior to voting to approve.

The group agreed that the goal should be to revise the document in time to present it to the ACD for review at their April 30, 2009 meeting. This will require scheduling a conference call meeting of the Ethics Subcommittee at the end of March or beginning of April in order to approve the document.

Ventilator Distribution Guidance

Kathy Kinlaw, MDiv

Bernard Lo, MD, University of California, San Francisco, Ethics Subcommittee Member

Robert Levine, MD

Dr. Lo provided an update on the development of the ventilator guidance document and raised issues for the Ethics Subcommittee to consider. These included questions about the role of preserving the functioning of society in decision making about ventilator distribution, questions about how to address various triage models, and questions about how to consider co-morbidities when making ventilator decisions. The draft document notes that the decision to place a patient on a ventilator will most likely be made quickly and according to pre-written guidelines. The document will aim to identify the values that should be taken into consideration when creating the guidelines for ventilator distribution. The document will not make specific recommendations regarding who should and should not receive a ventilator. Dr. Lo reported that progress on developing the document has been slowed by competing priorities for the Ethics Subcommittee members of the Ventilator Guidance Workgroup.

Discussion Points

Triage Models for Ventilator Distribution

Dr. Lo noted that various groups have made specific recommendations pertaining to the distribution of ventilators, and several triage models have been proposed to assess patients'

prognosis with or without a ventilator (e.g., the Apache Scale recommended by the American Thoracic Society (ATS) and the sequential organ failure assessment (SOFA) scale. Sometimes there are different protocols even in individual communities. There may be problems if two hospitals in the same city have different policies in that these different protocols will likely produce conflict and a sense of inequity within the community. It will be important to address the process for achieving community consensus on how to make decisions about ventilator distribution. In a public health emergency crisis, there will need to be consistent policies.

On the other hand, because values differ among communities, there may not be a “one size fits all” triage model. A concern is whether the available triage models take ethical principles into consideration. The ventilator guidance document can encourage revisiting the current triage models to determine whether they match the community’s values and adhere to ethical principles.

When the New York State Task Force created their triage criteria, they assumed that the ethically correct approach would be to use the limited ventilators as effectively as possible. “Effective” means that as few people as possible die on ventilators, and as few people as possible convert to chronic ventilator dependency. According to this model, the best use of ventilators in an emergency is to provide them to those people who need a “bridge” to restore respiratory function. Thus, the Task Force turned an ethical question into a medical question, relying on scientific means to identify patients for effective use of ventilators. The Subcommittee’s guidance document could examine the scientific aspects of triage protocols. Principles other than effective use of ventilators could be important, such as quality of life, the lifecycle principle, and others.

Some meeting participants expressed concern that a document about ethical issues may not be helpful if it is too abstract. At the same time, the document should not be too specific and presumptuous; it should find a middle ground. This guidance could analyze different triage models and the rationales behind them without reaching a level that infringes on decision-making. It was agreed that the varying triage models should be addressed in the document, but because the document focuses on ethical points to consider, it should avoid endorsing specific triage models.

Public Engagement and Community Input

Involving the community in the process of developing ventilator distribution protocols is a good strategy. Obtaining input from the public when policies are being developed can avoid chaos and dissent in an emergency situation. At the same time, public engagement should not be an “unfunded mandate.” Thus, the document will include a discussion of the need to bring the public into the process. It will be especially important to inform the public in advance of a pandemic that difficult choices will need to be made.

Part of pre-planning at the state level includes using federal funding to develop standards for alternate standards of care. A committee of experts may draft standards, which are then shared with larger professional groups for feedback, and then shared with the community. This process may result in a lack of input from the community in planning.

There was discussion regarding how to define “public” for the purpose of public engagement. It was noted that public engagement should include the lay public as well as the community of health professionals and healthcare workers.

Prioritization Issues

The previous Ethics Subcommittee document, "Ethical Guidelines in Pandemic Influenza," proposed priorities regarding influenza vaccines and antiviral medications. It suggested that individuals who play a key role in society, such that their loss would dramatically worsen the ability to cope with the pandemic (e.g., first responders and health care workers), should receive priority for receiving vaccines and antiviral medications. The arguments for vaccine and antiretroviral priorities are based on the persons' functional role in society, not as a motivation to take on risk. However, if a responder or health care worker is so sick as to need a ventilator, it is unlikely that he/she will be able to quickly return to their social function and contribute to mitigating the pandemic. Thus, the rationale used for setting priorities for vaccines and antivirals does not necessarily apply to ventilator distribution. The ventilator guidance document will include a discussion of how priorities for ventilators may differ from priorities for other scarce resources during a pandemic.

States will have to create prioritization strategies. Priorities can be set according to a scoring system or by using categorical solutions. It was noted that fairness will be an issue, as there can be a fine line between setting priorities for resources and stigmatizing groups that are not receiving resources. The categorical approach can be perceived as devaluing or discriminating against certain people as a group. Categorical decision-making could, however, be the most desirable approach in an emergency when decisions must be made quickly. The guidance document could be useful by anticipating concerns that may arise from categorical approaches.

It was noted that while the categorical approach to prioritization, for instance using the SOFA score, could be easy to understand and use, it could be less socially disruptive to prioritize according to the statistical likelihood of survival with a ventilator. The fairness of any allocation approach will be questioned. Decisions should be based on rational reasons rather than ability to pay, socioeconomic status, and others.

Additional Discussion Points

Some meeting participants noted that the notion of reciprocity seems to be absent from the document. Some people might be willing to put themselves at risk if they knew that they would have a better chance of surviving. In the original pandemic influenza ethics guidance, reciprocity and public benefit went hand-in-hand; whereas, in the case of ventilators, they do not. While the argument for reciprocity may not be compelling for decisions about ventilator distribution, a section of the document will address obligations to healthcare providers. These obligations might be expressed differently from reciprocity for provision of ventilation. The document will also address opportunities and obligations to increase the number of people who are available to provide care through cross-training and other means, such as volunteer licenses from state medical boards.

There was discussion regarding ethical issues relating to removal of patients from ventilators. A utilitarian approach for ventilator decisions will require a provision for re-evaluating patients' prognosis. This approach is a change from traditional practice in the intensive care unit. In general, routine medical practice involves saving the most lives in the fewest ventilator days possible. However, if a ventilator is needed for someone whose life has been shortened by another disease, should that person have the same priority as someone with no co-morbidities? The guidance document will need to consider the ethical dimension of these decisions.

Next Steps

The Ventilator Guidance Workgroup will produce a draft for the Ethics Subcommittee to review and discuss at their next meeting. Those present were instructed to e-mail additional comments pertaining to the ventilator document to Dr. Barrett by March 6, 2009.

Public Comment Period

At 4:51 PM on February 25, 2009 Mr. Jennings called for public comment in person or on the telephone. Hearing none, the agenda continued.

Responsibilities and Workload Expectations of Ethics Subcommittee Members

Ethics Subcommittee members expressed great interest in the public health ethics issues they are asked to address and they want to be useful to CDC, but they struggle with balancing their other responsibilities and the workload of the Subcommittee. The workload has increased in part as a response to their requests to address real, substantive issues of importance to CDC. In addition, as the Subcommittee is successful in developing useful ethics guidance, more areas of CDC are requesting their assistance. As more requests are received, prioritization of issues that the Ethics Subcommittee will be asked to address is needed. Ethics Subcommittee members wanted to explore options for having CDC staff take more responsibility for developing ethics guidance documents.

CDC is working to build capacity in public health ethics, as evidenced by the creation of PHEC and Center-level public health ethics teams. CDC staff derive a great deal of benefit and education from working with the Ethics Subcommittee to address public health ethics issues. In some areas, CDC staff have the expertise to take on the bulk of responsibility for drafting ethics guidance documents. However, this is not true for all programs.

It was suggested that CDC may wish to consider bringing in individuals with graduate-level or post-doctorate-level experience in ethics to work with the Ethics Subcommittee on writing tasks. Kathy Kinlaw and Leslie Wolf suggested that it might be possible to explore student placement at CDC as part of a collaborative relationship with Emory University and Georgia State University.

It was noted that the Ethics Subcommittee includes some of the highest-caliber professionals and writers and that their expertise should be utilized. Potential members should be made aware in the recruitment process that service on the Ethics Subcommittee will involve participation in developing ethics guidance documents. However, the Subcommittee should be judicious about the types of projects they accept. Dr. Barrett noted that there are established procedures for prioritizing issues brought to the Ethics Subcommittee. It was also noted that they may want to focus on creating shorter documents or brief statements rather than lengthy guidance documents.

In addition to exploring the graduate student option, another option could be to change the Ethics Subcommittee membership to include more junior-level people who might have fewer

obligations and could therefore devote more time to Subcommittee projects. The opportunity for career growth would be beneficial. However, the tenure years are stressful and those at a junior-level may not have the flexibility to participate.

Until and unless additional funding is secured to hire graduate students or fellows, then Subcommittee members should be aware that participation in workgroups on specific projects will require writing responsibilities. However, it was agreed that Ethics Subcommittee members will continue to work collaboratively with CDC staff to develop these guidance documents.

Wrap-Up and Final Comments

With no further business posed or comments raised, the meeting was adjourned at 5:03 PM.

Thursday, February 26, 2009

CDC Acting Director's Welcome

**Richard Besser, MD
Acting Director, CDC**

At 8:32 AM, Dr. Rich Besser greeted the group and reflected on his experiences working with the Ethics Subcommittee and PHEC. He stressed that ethics is integral to all of CDC's work, and expressed his hope that they would help CDC move forward in thinking about social determinants of health. He added his memories of Dr. Thomas Hooyman.

Discussion Points

There was discussion concerning securing additional resources for ethics activities at CDC and about whether CDC's budget was affected by the economic stimulus package. Dr. Besser explained that additional funds that may be available to CDC have been allotted in three categories: Prevention and Wellness, Immunization, and Healthcare-Acquired Infections. Workgroups at the HHS level have been established to address the process of distributing the funds. As an agency, CDC needs to make an ethical case for the inherent good in promoting health and in having a healthy population. The issue should also be considered from an economic standpoint as they discuss the benefits of a healthy population on the nation's economy. Returns on investment will not occur quickly.

Dr. Besser pointed out that funds are also available from other sources that can have an impact on health. For instance, in the area of electronic medical records, CDC supports adding public health fields to collect information about the population's health in addition to clinical data. Additional opportunities exist in the Department of Transportation (DOT) as they plan for roads that include bike paths and sidewalks, or from the Department of Education (DOE) that can include physical features to promote health.

Role of Social Determinants of Health (SDOH) in Health Reform

Introduction

Dr. Barrett began the session by briefly reviewing the draft charge for the Ethics Subcommittee's work on social determinants of health. The charge will be reviewed by the CDC advisory Committee to the Director (ACD) at their next meeting. Once it is approved by the ACD the Subcommittee can begin its work on this topic. The charge focuses on having the Ethics Subcommittee articulate the ethical value in promoting health through a focus on social determinants of health.

Overview of SDOH Research

Marilyn Metzler, RN, BA
Social Determinants of Health Analyst
CDC/McKing Consulting

Ms. Metzler provided an overview of current research on social determinants of health and provided some detail on the recent report from the World Health Organization Commission on Social Determinants of Health. This Commission reached three overarching recommendations: 1) improve daily living conditions; 2) tackle the inequitable distribution of power, money, and resources; and 3) measure and understand the problem and assess the impact of action. The overarching questions facing CDC pertain to the following:

- How to balance the interests of both science and social justice where tensions exist
- How to balance the interests of "health for all" and health equity
- What counts as evidence, and who decides
- How to create a sense of urgency

Discussion Points

The social gradient literature indicates that those who are at lower levels of a gradient, even if they are not in poverty, are worse off than those at the next level of the gradient. The group agreed that this question is important when considering social justice issues. The issues of poverty and deprivation and social gradient should be kept separate.

It was noted that women are at a comparative social disadvantage in almost every society, and yet women live longer than men. The need for more research on the impact of biology and social structure on health outcomes was pointed out by various members of the group.

One member of the group pointed to arguments that in societies that are more socially unequal, everyone is "worse off." It was noted that the idea that "inequality is bad for everyone" is a source of disagreement in the field.

It was pointed out that there is a tension between our current scientific knowledge regarding the health impact of social injustice and our desire to intervene to improve ill health caused by social

injustice. While science may currently not be able to show all the mechanisms and pathways of how inequality and poverty impact health, social justice arguments and linkages can be made.

There was a question about what population intervention studies have shown regarding impact on reducing health inequalities. Dr. Metzler indicated that there are some promising ongoing projects; however, outcome data are not currently available.

Tools for Understanding Health System Performance: CDC's *Health Run* Game

Bobby Milstein, PhD, MPH
Coordinator, Syndemics Prevention Network, CDC

Dr. Milstein presented *Health Run*, the health protection game developed by CDC. The game is based on a vision of population health and healthcare as a system of interacting causal forces. For further information, the URL is: <http://www.cdc.gov/syndemics>

Discussion Points

Dr. Milstein pointed out that developers of the game took an operational approach to the definition of health equity, using metrics such as the fraction of overall mortality and unhealthy days per month that is attributable to those in the disadvantaged subgroup of society. The game does not address issues of the health gradient, but rather specifies just two strata of society: the advantaged and the disadvantaged. These strata are approximated by household income. The measure of inequity is the fraction of the total unhealthy days or total deaths that are attributable to the subgroup of “disadvantaged.” This simplified portrayal is sufficient to raise basic questions about health equity, differential vulnerability, justice, and the likely consequences of various policy options. Players try to achieve positive results simultaneously along four dimensions: morbidity, mortality, health equity, and health care spending. As the game moves forward, players can appreciate the inherent connections and occasional tensions among health status, equity, and cost.

While the United States often speaks about “disparities,” other countries more commonly refer to “inequalities” or “inequities” in the area of population health status and healthcare. The term “disparity” may not have the same moral value as “inequity”, which connotes a lack of fairness in the distribution of health outcomes, opportunities, and/or agency.

There was a question about whether the game could incorporate lessons from countries that have decided to adopt universal healthcare questions. Information used to design and calibrate the model was informed by international research on the effects of universal coverage and other policies, but the game itself is tailored to represent the specific structure of the U.S. health system.

When used appropriately, models bring a greater degree of structure and evidence to policy planning and evaluation, which in turn can be a valuable aid to thinking and learning. There are numerous tests to establish confidence in simulation models, which include but are not limited to re-creating historical trends. The standard for credibility is not perfection or “validation” of the model, but rather its realism and utility versus the un-aided mind. Developers and users also have a responsibility to prevent potential misuses the model and its results.

Dr. Milstein pointed out that the game in question, like all models, is imperfect by design, but should be helpful in stimulating discussions and supporting our collective decisions about U.S. health system reform.

Addressing the Social Determinants of HIV, Viral Hepatitis, STDs and TB

Kathleen McDavid Harrison, PhD, MPH, FACE

Associate Director for Health Disparities

National Center for HIV/AIDS, Viral Hepatitis, STD and TB Prevention (NCHHSTP), CDC

Dr. McDavid Harrison provided a summary of the theoretical framework and background of the Social Determinants of HIV, Viral Hepatitis, STDs and TB consultation held in December 2008, including its purpose, its process and outcomes, and next steps. The consultation was successful in identifying key priorities in four activity areas, and is helping to develop a social determinants of health strategy for NCHHSTP with clear goals and objectives. The consultation also demonstrated partners' commitment to address social determinants of health and to broaden conversations about those topics.

Discussion Points

One of the aspects of the charge to the Subcommittee is to examine ethical issues in partnerships. There was a request to receive materials from the NCHHSTP Consultation to aid in those deliberations.

Concern was expressed that while conversations are on-going regarding social disparities and their impact on health, the depth of the issues may not be understood. Inequality has grown in America in the last 30 years at an alarming rate, and there does not appear to be a commitment in this country to address social inequality. For instance, phrase "sharing the burden" in the recent presidential election was not met with overwhelming support. Economic inequities drive health problems, and partnerships are critical to address the question of why poverty exists in America. A national conversation is needed to change the social vision.

While CDC cannot eradicate poverty on its own, the agency and individual centers can do their part to raise the issues, stimulate discussions, and have an impact as best they can as they work to elevate the question to higher levels.

Work in social determinants of health has focused on community partnerships in the past, and the point was raised that the inequality of the distribution of money, power, and resources must be addressed.

One of the strategies of the NCHHSTP has been to support programs to train racial and ethnic minority groups through internships and to develop training programs pertaining to social determinants of health so that a new cadre of public health professionals can move forward in the field.

The literature in social determinants of health directly challenges the distribution of power, wealth, and money in society. Social inequality is a causative pathway to poor health. Opposition and criticism to this approach is inevitable. There is a need to shift the cultural perspective and to reeducate the public.

Thus far, efforts in social determinants of health have focused on process interventions rather than on content interventions, which would address social change. It would be an interesting challenge to convene several groups to list specific ways to make inroads on social determinants. For instance, funds that are presently directed toward health could be directed toward education, which makes a difference in health outcomes, crime outcomes, and other social factors.

This work will require a paradigm shift for the United States. Conversations must take place at high levels of government, and partners will need to develop a plan for tackling disparities.

The Ethics Subcommittee role in this process will be to make persuasive ethical arguments on the importance of examining social determinants of health as part of health reform efforts. Because there is not consensus in the American culture, the Subcommittee can set forth arguments, rationales, and options. Further, the Subcommittee can provide input regarding language and terminology. There needs to be more clarity at CDC on the terms used and what CDC's role should be.

Social Determinants of Health and Social Determinants of Equity

Camara Phyllis Jones, MD, MPH, PhD
Research Director on Social Determinants of Health
Division of Adult and Community Health,
National Center for Chronic Disease Prevention and Health Promotion
CDC

Dr. Jones presented a model of social determinants of health, social determinants of equity, and levels of health intervention.

Discussion of the ACD Charge on Social Determinants of Health

Clarifying Language and Terminology

Terminology is important, given that terminology is not only a matter of words, but also a matter of concepts. Ethical concepts are different from scientific and political concepts. There are inter-relationships between the values of ethical concepts and other concepts.

Many concepts need to be clarified, such as: the difference between equity and equality; what is unfortunate and what is unfair; the question of opportunity; and others. The charge from the ACD asks the Subcommittee to address conceptual foundations for the discussion. Topics such as power can be framed in the literature and viewed from an operational standpoint.

CDC's work in this area should be encouraged. Getting the language of equity into public discourse via a discussion of health disparities is an important opportunity.

There is no language in bioethics to deal with issues such as intergenerational justice.

There should be a distinction between conceptual clarification and questions of justification of values. For instance, the equity/equality distinction is a conceptual question.

Preliminary Discussion about the Potential Contributions of the Ethics Subcommittee

Members of the Ethics Subcommittee indicated that they cared deeply about the issue of social determinants of health and that they hoped to be useful to CDC. However, they would need more direction from CDC about how they could be most useful.

It was suggested that the Ethics Subcommittee may be helpful if they tackle the question of the impact that ethical concepts and language can make in politics and policy. Ethical arguments are not sufficient to eliminate political and social obstacles, but ethical discourse can be used in policymaking and public education and information.

CDC may launch demonstration projects or trials of interventions designed to reduce social determinants and to show changes in health outcomes. There are ethical issues involved in designing and carrying out this kind of research. Work of this type is part of CDC's agenda, and the Subcommittee might be able to identify these ethical issues in advance to assist CDC.

Some of the questions raised will be ethical, but many others will be epidemiologic in nature, and the Subcommittee should focus on helping CDC create a "roadmap" for bringing all of the issues together and moving them forward.

Another dimension of the Subcommittee's work will be to articulate why work in social determinants of health is ethically important. The literature has supported this approach for a long time, but a convincing ethical argument is needed in language that the public can understand.

There was discussion regarding whether the Ethics Subcommittee could assist in building CDC's agenda around social determinants of health.

There was discussion regarding the model that the Subcommittee should use to address questions of social determinants of health. Historically, the Subcommittee's products have been well-received by CDC, so they might consider a similar model for social determinants of health.

In a manner similar to the ventilator document, the Subcommittee could pose different models and discuss their implications in a value-neutral manner.

Caution was expressed regarding allowing ideology to drive policy. The Subcommittee should produce a consideration document that is argument-based.

The Subcommittee's previous work may not serve as a model for this task. The Subcommittee's other products have been examinations of ethical implications of a given problem. This task, however, is a consideration of the body of knowledge of social determinants of health and a mapping of the ethical domain that follows from that body of knowledge. The Subcommittee can prepare CDC for the complexity of the issues.

There needs not only to be conceptual clarity about the topics to be addressed, including inequity and disparities, but also the considerations that go into action guides. For instance, an ethical perspective could guide CDC's collaborations and connections with federal and other partners.

This topic is important to many Subcommittee members. They must separate their personal commitment to abolishing or minimizing disparities from their role as a Subcommittee member. They could likely be of most help in the role of clarifying concepts.

The issue of social determinants of health is an issue of moral will and vision and also an issue of political will and vision. The social determinants perspective makes us look at ethical questions in terms of power and social structure rather than simply in terms of individual behaviors and choices. When one adopts this perspective, ethical concepts are applied in new ways to epidemiology and public health. For instance, life course data suggest new meaning for the term “equality of opportunity.” The emerging knowledge base on social determinants of health will allow us to rethink some of our fundamental beliefs, such as the concept of personal responsibility for health status. Also the concept of equity takes on a different meaning when we view it as an aspect of people living together in a particular context rather than as a distribution of commodities.

It was noted that there are opportunities for “cross-fertilization” between social determinants of health analysis and the perspective of the environmental justice movement.

Suggested Amendments to the Draft Charge

It was pointed out that the draft charge is not clear regarding what is expected of the Subcommittee. However some suggested that the language of the charge should remain broad in order to allow Subcommittee workgroups with some flexibility on how to proceed.

It was suggested that the Subcommittee could be most helpful in specifying an ethical basis for addressing social determinants of health.

It was decided that the language of the charge would be amended to emphasize articulating the ethical justification for doing this work. The ethical issues surrounding health reform are different from justifying taking the approach.

Summary of Discussion

There emerged from the discussion agreement that it would be appropriate for CDC to address social determinants of health but that it should be done in a rigorous and scientific manner. The Subcommittee can help CDC articulate the values that underlie the decision to take on social determinants of health.

Public Comment Period

At 12:39 PM on February 26, 2009, Dr. Hood called for public comment. Hearing none, the agenda resumed.

Follow-up on Ongoing Activities

During this session, Dr. Daniel McDonald Office of Workforce and Career Development (OWCD), presented an update on the web-based course on Public Health Ethics. OWCD will begin a pilot-test in March and April with Atlanta-based CDC employees and international employees.

Dr. Barrett noted that at the end of June 2009, Mr. Jennings, Dr. Arras, Dr. Gamble, and Dr. Kinlaw would rotate off of the Ethics Subcommittee. CDC is in the process of gathering names of new prospective members. Attendees were instructed to e-mailed suggested individuals to Dr. Barrett by March 6, 2009.

Procedural Issues and Meeting Wrap-Up

The next joint meetings of the Ethics Subcommittee and PHEC will be:

- June 17-18, 2009
- September 23-24, 2009

With respect to next steps, Ethics Subcommittee and PHEC members were reminded to submit their comments on the following by March 6:

- Charge from ACD regarding Social Determinants of Health
- Travel Restrictions Guidance Document
- Ventilator Guidance Document
- Recommendations for new Ethics Subcommittee members

With no further business posed or discussion raised, the meeting was adjourned at 12:51 PM.



Certification

I hereby certify that to the best of my knowledge, the foregoing Minutes of the February 25-26, 2009 Ethics Subcommittee Meeting are accurate and complete.

Date

Bruce Jennings, MA
Chair, Ethics Subcommittee

Attachment 1: List of Attendees

Day One: February 25, 2009

Ethics Subcommittee, Advisory Committee to the Director

John Arras, University of Virginia
Vivian Berryhill, ACD Member, National Coalition of Pastors' Spouses
Vanessa Northington Gamble, George Washington University
Robert Hood, Co-Chair, Florida Department of Health
Bruce Jennings, Chair, Center for Humans and Nature
Nancy Kass, John Hopkins University
Kathy Kinlaw, Emory University
Bernard Lo, University of California, San Francisco
Leslie Wolf, Georgia State University

Centers for Disease Control and Prevention

Barrett, Drue (Designated Federal Officer, Ethics Subcommittee)
Karen Bouye (by phone)
Marty Cetron
Richard Dixon
Dave Dotson (by phone)
Roberto Garza
Karen Gavin (by phone)
Neelam D. Ghiya
Sara Giordano
Gail Horlick
Annie Latimer (by phone)
Lisa Lee
Mary Leinhos
Daniel McDonald
Fred Murphy
Mary Neumann
Leonard Ortmann
Tanja Popovic
Lewis Rubinson (by phone)
Anne Sowell
Antonia Spadaro (by phone)
Sharon Martin Tart (by phone)
Brandy Wright

Members of the Public

Robert Levine, Yale University, Ethics Subcommittee Consultant (by phone)

Day Two: February 26, 2009

Ethics Subcommittee, Advisory Committee to the Director

John Arras, University of Virginia
Ronald Bayer, Columbia University
Vivian Berryhill, (ACD Member), National Coalition of Pastors' Spouses
Vanessa Northington Gamble, George Washington University
Robert Hood, Co-Chair, Florida Department of Health
Bruce Jennings, Chair, Center for Humans and Nature
Nancy Kass, John Hopkins University
Kathy Kinlaw, Emory University
Bernard Lo, University of California, San Francisco
Leslie Wolf, Georgia State University

Centers for Disease Control and Prevention

Drue Barrett (Designated Federal Officer, Ethics Subcommittee)
Richard Besser, Acting CDC Director
Scott Campbell
Linda Carnes
Casey Chosewood
Richard Dixon
Dave Dotson (by phone)
Neelam D. Ghiya
Sara Giordano
Alvin Hall
Kathleen McDavid Harrison
Susan Hunter (by phone)
Camara Jones
Annie Latimer
Daniel McDonald
Marilyn Metzler (by Envision)
Bobby Milstein
Fred Murphy
Mary Neumann
Leonard Ortmann
Tanja Popovic
Stevenson Richardson
Carol Simon
Thomas Simon (by phone)
Anne Sowell (by phone)
Antonia Spadaro
Sharon Martin Tart
PerStephanie Thompson
Mark White (by phone)
Brandy Wright (by phone)

Members of the Public

None